Health Applications of the National Information Infrastructure
Contract N01-LM-6-3539
HealthAware: An Integrated Health and Health Care Information Network

FINAL REPORT

1. Project Summary

This project aimed at stimulating the convergence of two trends, by establishing an integrated network for health, wellness, and health care called "HealthAware" to tie together a) the consumer health information resources of a community with b) the information resources of an emerging regional healthcare network. Specifically, HealthAware was intended to link community-oriented resources at Boston College (BC) and the services of the Partners HealthCare System, and specifically Brigham and Women's Hospital (BWH) to serve as a testbed network. The foci of the testbed projects were in five areas:

- Drug/substance abuse
- Breast cancer
- Orthopedics/sports-related injuries
- Pregnancy/prenatal care
- Cardiovascular diseases (substitution for infectious disease focus area, as approved by contract modification)

2. Background

HealthAware™ is a Web-based information resource for consumers which provides up-to-date content about health, wellness, and health care. Unlike many consumer health sites, HealthAware seeks to "close the loop" when the need for care arises, by providing personalized information through risk assessments and other interactive tools, providing recommendations for referral or additional information through links to the local health care enterprise, and facilitating requests for and scheduling of referrals.

To implement these features, a component-based strategy was used in which a core set of tools has been implemented, and which provides flexibility and expandability, in terms of ease of adding future features. Editing tools are used to author and update content in module-specific database files. A distributed authoring/editing approach is used that facilitates editorial review and approval analogous to traditional publishing; upon editor approval, content is published in Web-accessible format. Dynamic page generation from the databases enables content to be managed without the need for a Webmaster, and ensures a consistent look and feel for presented pages. The system is designed to enable both external content and locally developed materials to be incorporated, with appropriate disclaimers and acknowledgments.

3. Goals

This project had the following goals:
- Establish an information resource on health, wellness and health care for consumers
- Link the resource to local health care systems when need for care arises
- Understand consumers information needs and usage patterns
- Evaluate opportunities for improving quality and appropriateness of referrals

HealthAware was intended to help consumers and patients:
- Obtain personalized information through interactive tools
- Close the loop in their health care problems by:
  - Being more than a generic information resource
  - Providing recommendations for referral
  - Connecting patients to the provider network
  - Facilitat requests for referral or appointment

4. Approach

4.1 System Design and Development

Requirements Gathering
This phase began with a review of the existing web-based consumer health sites and included interviews with physicians, consumers and patients (of the BWH), heuristic evaluation of current websites, usability testing and market research on use of health care services in the Boston area and BWH.

Review of web-based consumer health sites (May 1998)
Newsweek article (Feb 1998) criticizes the poor quality of health information on the web and cites the following example: Search for kids' fever yielded near 1000 sites; based on review, only 41 met up-to-date guidelines.

There were lots of sites with medical content (>20,000), fewer with risk assessment (8) and none with an online referral service and resource locator. The user interfaces of the systems below, yielded poor results on heuristic evaluation, confirmed by usability testing (3 users). These interfaces have since changed, as have the content and actual sites.

HealthWise Knowledge Base
- provided cancer info mostly from PDQ
- very limited
- gave bits and pieces of info without 'whole picture'

IntelliHealth (Johns Hopkins)
- provided limited content info (rapidly developing more)
- content took a breadth-first approach, rather than depth-first (HealthAware)
- had on-line chats, e-mail, personalized news, test yourself sections
- sold home products
- no graphics (working with ADAM.com)

HealthScout
- provided 'filter' for users by recommending good, relevant sites based on categories they chose
- mostly headlines (news and magazine articles)
- poor description of links
- articles from interviews, NIH, newspapers
- limited content from staff of 25 writers (hunter-gatherers)

MSNBC
- virtual checkup (risk assessment tool) – not totally accurate
- poor interface (difficult to navigate)
- no content
- Past and present news items (jumbled together)

Mining Co.
- Site of links only
- Reviewed by their staff
- Minimal content development (medical writers, not physicians/clinicians for the most part)

Health Online
- focus on four areas – newstand, library, briefs and kitchen
- basic health info, short blurbs, no details

Patient Education Institute – Xplain
- detailed medical info related to procedures, diagnosis, prognosis
- no other services (based on demo and description)

Physician Interviews

To better define the requirements of the system, interviews were conducted with four of the physicians, also informaticians, involved in the writing and development of this grant proposal.

Question 1: What was the impetus to develop the HealthAware system?

The four physicians had similar comments and concerns. As physicians, they realized that patients rarely get complete answers/explanations to a question during an office visit and gain limited specific knowledge from consumer-oriented publications for various reasons:

- The visit is rushed from the physician's perspective. Physicians have less time to spend talking with a patient because management (hospital, departments, HMOs) largely dictates their schedules. They are expected to see and treat a certain number of patients per month or year and management-developed guidelines monitor this. As a result, there is usually a specific time allocation for each type of visit, e.g., treatment or general exam.
- The visit is rushed from the patient's perspective. Because of the time constraints imposed upon a medical visit (mean duration of a primary care follow-up visit = 10.9 minutes), patients don't usually have time to process the information given to them regarding diagnosis, treatment options, etc. Also, the emotional and psychological duress makes it difficult to ask the 'right' questions at that time. Moreover, other questions arise days later, after they've had a chance to think about what they've been told, do some reading or speak to others.
- Patients frequently consult medical texts, consumer health books and health-related magazines to get answers to their questions, both general and specific. This enables them to learn much about a given problem, but might not have any impact on that particular individual's situation. Getting personalized, custom-tailored information would fill the gap and possibly improve the patient's health as well as communication between patients and providers.
- Current information and media are not tailored to a patient's particular needs based on their diagnosis, literacy level or information needs.
- Having an online method of referral was also a major goal, which speaks primarily to the problem of continuity of care with patients. The full circle of education, primary prevention, triaging by medical care providers and referral to specialists could be provided by an information system in a continuum.

Question 2: How were the design decisions made?

- The four interviewees explained that a goal of medical informaticians is to improve quality of care and service through the use of technology. Knowing that interactive communication between patients and providers was possible, they considered various scenarios for proof of concept. People were starting to use e-mail to communicate with their physicians, so that feature was considered from the outset. The National Cancer Institute (NCI) implemented an "ask-a-doctor" service that was also receiving some attention at the time. It was hard to know how valuable and acceptable these types of services would be, so they decided to focus a grant on these very issues.
- Other features included technology that was more widely implemented, such as bulletin boards, which have at least a ten year history of consumer use (among more sophisticated users)
- In 1995, the WWW was becoming available , so they decided to make HealthAware a web-based telemedical application. The implications were lower cost for a user and universal access (if connectivity was enabled and the user had a newer model PC). Other technologies such as CD-ROM and floppy disks involved greater production costs, expensive and labor-intensive maintenance, slower updates (new updated disks released only once/twice a year) and assumed that a user had the ability to install/load software. The success of services such as AOL also reinforced the decision to go with a web-based application.

With the above considerations in mind, the following features were proposed:

- Content intended to provide incentive for a consumer to come to the site, get accurate, up-to-date information and learn about anatomy, tests, treatments and more. A growing number of sites existed, but very few were providing a systematic approach to development and update of high quality information. The biggest obstacle for users was the variable quality of information on the WWW, with little ability to judge quality of particular information.
- Risk assessment and guidelines – patients can access custom-tailored information and guidelines based on their current state of health (for a given set of conditions)
- Referral tools
    - ⇒ mediated referral interaction with a medical professional via e-mail (anonymous or not) and ask-the-expert sessions. Here, patients can get more specific information on the seriousness of a certain condition, in particular regarding whether they need to see a physician.

⇒ non-mediated referral provided by interaction with other users via chat groups, bulletin boards and answers to frequently asked questions.

- To offer the most effective service possible, it was best to focus on regional resources – for example, local physicians, support groups and programs.

Question 3: How will the design change the patient-provider relationship?

- It will result in better communication with patients they won't feel as restricted as they do during appointments and telephone calls and will be better informed. Guidelines and procedures can be reviewed with thepatient. The physician will also ensure that the patient has the latest information/guideline.
- The system might reduce a patient's dependence on the physician to be his or her sole knowledge source, and improve the physician-patient relationship logistically by alleviating phone tag and ime constraints, and the ensuing frustration.

Question 4: Who was on the design team?
The design team was multidisciplinary and included physicians from various specialties, informaticians, a sociologist, software engineers, web programmers, a graphic designer, a human factors engineer and a technical editor.

Patient Interviews
Four interviews with patients were conducted to glean their perspectives on this type of web-based system and user capabilities, and six interviews to asses expectations of the physician-patient relationship. After a brief description of the HealthAware project, the following questions were asked:

1. Would you be interested in accessing this type of system.
2. What type of user would want or use HealthAware?
3. Give five adjectives to describe your relationship with your physician (any and all of your physicians). How will HealthAware affect this, if at all?

Question 1: Would you be interested in this type of system?
All four interviewees agreed that this would be a welcome improvement and wanted to sign up immediately. They currently 'hunt and peck' for as much information as they can get from friends, colleagues, newspapers and books, but realize that some sources are better than others. Unfortunately, they do not have the means to differentiate good information from bad. They rely on their physician to help make sense of all the information and this usually entails additional office visits, phone calls and even asking friends to get this information from their own physicians "…I have this friend who…..". HealthAware will help make patients more independent and give them a chance to prepare before an appointment, know what is expected and come to an appointment with the right questions in hand.

Patients were in agreement with the physicians' comments about rushed visits, but didn't blame the physicians for this in most cases, instead, they faulted the hospitals and HMOs.

Question 2: What type of user would want or use this system?
Interviewees all felt that at this point in time, anyone with a medical problem or concern would want to access this type of system. To be really useful, it should include information relevant to the physician's practice and reflect the latest information. The users would need to be computer literate, have access to a computer, be able to read and write in English and have some knowledge of the Internet.

Question 3: Give five adjectives to describe your relationship with your physician (any and all of your physicians). How will HealthAware affect the relationship, if at all?

Part I: Adjectives used by the eight respondents:
Disconnected, impersonal, informative, frustrated, indirect, adequate, disinterested (lack of caring), satisfied, advisory, intimidating, paternalistic and authoritarian (some of these were mentioned by more than one interviewee).
Part II: Seven of the eight interviewees believed that HealthAware would improve the physician-patient relationship by:

- making them feel more involved in their health care
- having their physician take them more seriously and answer their well-thought out questions
- making the interaction less paternalistic and, by having access to treatment options and guidelines,
- making it less authoritarian.

One person felt that this would complicate their relationship with their physician and might even jeopardize their care. He did not want to be in a position where he would be 'second guessing' his doctor and asking questions that were not relevant.

Market Research
Market research was conducted to gain a better understanding of why people come to the BWH for service, how they access services and what the major health concerns are in the greater Boston area.

BWH Marketing

Top 12 reasons why people call the physician referral service at BWH
Reputation of the hospital
Multiple service lines
Center for Women and Newborns
Quality of care
Media exposure, e.g., Dateline, Chronicle features
Cutting edge technology
Physicians' reputations
Website inquiries
Presence of multiple locations satellite sites and ease of access
Research studies conducted at BWH

Teleservices receives calls as a response to: ads, direct mail, health education lectures, radio announcements. Approximately 2500 calls are received per month, and approx. 800 make appointments (this fluctuates seasonally). 80% are first time callers and come in via the referral service.

HealthShare data - BWH discharges by service line, FY 1997 (top 10 only)	
Obstetrics	21.7%
Neonate	20.3%
Cardiology	8.8%
General Surgery	8.4%
Orthopedics	7.2%
Thoracic Surgery	5.8%
Gynecology	3.8%
Pulmonary	3.8%
Gastroenterology	3.6%
Oncology	2.4%

HealthPlus Data for the Greater Boston Area (n=4,084)

Healthcare activities of respondents in the past 12 months	
Routine physical exam	52.7%
Cholesterol test	32.4%
PAP smear	30.2%
EKG	20.1%
Visited an emergency room	19.5%
Mammogram	18.9%
Outpatient rehab treatment for illness/injury	9.9%
Prostate cancer test	9.0%
Attended a health education talk or program	8.0%
Attended a fitness/wellness program	7.9%

Health condition of Respondents	
Seasonal allergies	27.8%
Arthritis or rheumatism	19.8%
Chronic allergies or sinus troubles	19.1%
Hypertension	18.7%
Stomach ulcers, heart burn	11.7%
Hemorrhoids	11.0%
Sciatica or chronic back problems	10.5%
Migraine headaches	10%
Depression	9.2%
Dermatitis	7.7%

Content Development

Consumers put a lot of emphasis on good medical content. Based on our literature review and preliminary interviews with patients, it is apparent that although there is a growing supply of health-related information on the WWW, the quality is often variable and unreliable (1-5). Many sites are not maintained by medical professionals and provide outdated guidelines and recommendations and in some cases, totally inaccurate information (4). Consumers feel that there is not enough information on some topics, and that much of it is unreliable. In the case of health-related information, misinformation could become life-threatening (3) Recent studies have focused on this potential danger, and have looked specifically at quality of information, as provided via mailing lists, newsgroups and e-mail communication between patients and doctors (3-15). Patients also feel that their doctors don't tell them everything they need or want to know (12).

A user-centered design approach was used to develop content for the five areas of focus for this project.
Strategies used for content development included:

- User-centered approach to defining the requirements for new educational materials
- Link to material that already exists (must be approved by content expert)
- Desirability of a blend of both generic content and local content with direct links to local resources.

(i) In the first phase, 6 consumers were surveyed about the quality and usefulness of the pre-existing HealthAware content, quality of content from other sites and how this assessment would affect their decision-making with respect to becoming more informed about their health and accessing services.

(ii) Online interviews were conducted with 5 participants to help understand how users process medical content and what the basic information needs are.

(iii) Participation in various health-oriented chat rooms helped us better understand the content issues with which people were dealing.

(iv) Exit interviews were conducted at BWH. After exiting the clinic, willing participants were asked a series of questions about their information needs (we confirmed that all participants were patients of the clinic and had just seen a physician):

- Was your need for information satisfied?
- Did your doctor give you any information to read or suggest any information resources?
- Do you have any additional questions for your doctor?
- Was your doctor able to answer all of your questions?
- If you had an additional 30 minutes with your doctor, what would you ask, or talk about?
- Where do you look for medical/health information?

(v) Residents and 4th year medical students collected questions commonly asked by patients in clinic

(vi) We met with physicians

Once the requirements for consumer content were understood, templates were developed to structure the type of content needed for the HealthAware site. HealthAware project staff worked closely with physicians to develop content that addressed the patients' and consumers' concerns. There was clearly a gap between the type of content that existed (and the content that physicians were willing to provide, e.g., their latest review article from NEJM) and the content that patients/consumers requested.

Readability of some of the HealthAware medical content was deemed too difficult by users at Boston College. Content had to be rewritten several times for easier readability. The Flesch-Kinkaid reading scale was used to gauge content readability. Although our testbed is a college campus, reading scales were reduced to 10^{th} grade to make the material easier to comprehend and then again to 8^{th} grade level. This is consistent with our literature review (16,17). Although the mean reading education level in the USA is at grade 12.6, the mean literacy level is at or below eighth grade for medical content. Other factors confounding the literacy issue include emotional anxiety about one's health and personal relevance, i.e., what does this mean for me? Methods used to assess reading level included Flesh-Kincaid, McLaughlin SMOG and Gunning Fog, –for which accuracy is reported to be within 1 grade level.

Authoring/Editing System for Content

- We developed a set of structured forms which guide content entry into a database, thereby allowing easy uploading, simple maintenance, and re-use of content
- Dynamic page generation enables content to be entered without a webmaster
- The editing environment ensures consistency and fosters a unifies presentation format
- The authoring system includes a distributed author/editor approach supporting a built-in review process. Prior to publishing content on the website, the editor must approve and/or have the material approved by designated individuals, allowing for implementation of institutional quality assurance procedures.

Development of the Web Authoring System:
A component-based web authoring system was developed to support the publication of information to the Web by users regardless of prior programming experience. The system consists of an underlying foundation and a combination of modular components ('blocks') facilitating easier implementation, modification, maintenance and future development. By separating content entry, administration and output, site and content maintenance can be distributed and simplified.

Details of the three divisions:

(i) Content Entry Blocks – Form-based content entry pages have been developed to accommodate the varying information types on the Healthaware site. These forms allow content experts to enter information directly into the system in free-text format – knowledge of web programming is not required. This distributes the workload and guides content experts through the site structure and hierarchy as well as giving them the ability to enter new/updated text at will.

(ii) Administrative Blocks This area allows one to specify top-level information such as identifying new users, defining disclaimers and creating the site outline.

(iii) Output – The look and feel is coded into templates. Each page has a corresponding template that loads the relevant content from a database (dynamically generated content). This allows a small number of template files to generate all the pages in the site dynamically with the most current data in the database.

Interactive tools

Chat group

- BasiChat, a commercially available chat program, was purchased and integrated into the HealthAware site.
- In addition to chat sessions scheduled with medical professionals, users can log into the service through each module at any time and 'chat' with each other.
- Through the authoring system, scheduled sessions can be easily entered and automatically displayed on the site to highlight the service to users.
- This feature was subsequently removed for legal concerns. Since the chat sessions are not moderated, they can be a source of misinformation for patients and consumers and therefore a potential liability for the hospital

Anonymous e-mail

- Labeled "MedMail" on the site.
- Users can post messages to the site and retrieve responses.
- Users have the option of remaining anonymous or using their names. Secure service technology was licensed for this tool (from Thawte, now part of Verisign).

Bulletin Board System

- Labeled “Message Board” on the site.
- In order to provide more customizable features and stronger database support the bulletin board system was rewritten in Cold Fusion 3.1 and backed by an SQL server database (to record all information).

Search

- Ultraseek software was licensed for use, but not fully installed.

Health recommendations (risk assessment)

- Labeled “Am I at Risk” on the site.
- The purpose of our risk assessment tools was to help direct the patient/consumer to the next step in their medical care and help them decide whether they needed to see a doctor.
- No diagnostic information was provided, just information on risk, where appropriate
- All five content areas have different types of risk assessments and recommendations

We have developed the following interactive questionnaires to help consumers make decisions about whether they need to consult a health care professional:

- Cardiovascular disease
  - Am I at risk for Heart Disease? (Based on the Framingham Heart Study)
- Pregnancy and prenatal care
  - What type of medical provider do I need?
  - When should I see my medical provider? (list)
  - When to call your doctor after 20 weeks (list)
  - When to call your doctor before 20 weeks (list)
- Breast disease
  - For screening, what is my recommendation?
- Substance abuse:
  - STEP (Sobreity, Treatment, Education and Prevention Test) – This questionnaire was developed by the North-End Waterfront Addiction Recovery Center in Boston MA, and is used on College Campuses
  - CAGE survey – Cut down, Annoyed, Guilty, Eye-opener. This questionnaire is also used on college campuses and is a little more comprehensive than the first one (STEP). Ewing JA. JAMA 1998 Dec 9;280(22):1904-5.
  - Drinking Habits (social, problem, alcoholic)
  - Is danger ahead in your relationship? (points of concern)
  - Warning signs of alcohol or other drug problems (list)
  - Tips to avoid an alcohol problem (list)
- Sports injuries:
  - I hurt my ankle/foot, what should I do?
  - I hurt my shoulder, what should I do?
  - I hurt my knee, what should I do?

News

- Items to be posted were reviewed/suggested by physicians and links then added to the site.
- Items were updated every couple of months, and even this was not frequent enough to keep up with the demand for the latest news.

FAQs

- Topics were defined by patients and physicians.
  - Labeled "Questions" on the website
- An FAQ entry form is included in the authoring system. This allows system users to define FAQs and assign them where appropriate in the site.
- The FAQs link to relevant content, risk assessment tools and resources, where appropriate.

Development of tools for referral and access to local resources

Users were presented with a list of resource types, which varied by topic, along with a core set of hospital information links: directions, referral information, parking information, etc.

- Cardiovascular disease
  - Find-A-Doctor, Educational Programs and Hospital Information

- Pregnancy and prenatal care
  - Find-A-Doctor, Find-A-Midwife, Educational Programs and Hospital Information

- Breast disease
  - Find-A-Doctor, Educational Programs, Support Groups, Related Links and Hospital Information (included a virtual tour of mammography at BWH)

- Substance abuse:
  - Treatment Centers, Organizations/Societies and Hospital Information

- Sports injuries:
  - Find-A-Doctor and Hospital Information

5. Deployment and Evaluation

5.1 Boston College

To establish the degree to which the content imparted useful health knowledge, pre-test and post-test surveys were conducted on campus, along with focus group studies. Participants (students, employees and faculty) were asked to complete a pre-test survey about their health attitudes, knowledge and health behavior prior to accessing the HealthAware website. Once the consent forms were signed and pre-test survey completed, participants used the HealthAware website for 2-3 months and were then asked to complete a post-test survey. The purpose of the surveys was to see whether web-based health content would educate participants, stimulate interest and effect a change in their health behaviors and attitudes.

The results of these studies are limited because participants are self-selected, data are self-reported and no control group was studied (users served as their own controls). Effects of increased knowledge cannot be attributed solely to the use of the HealthAware website. Perhaps participants were made aware of certain health risks and issues and paid more attention to them in the media, or even sought out other sources of information. We report on the general demographics of this population along with the results of the pre- and post-test surveys by topic.

Substance Abuse

Students were recruited from Biology and Sociology classes

Gender

66% Female
34% Male

Ethnicity

4.3% Asian
0.7% Caribbean
2.2% African
5.1% Hispanic
87.7% White

Religious Background

73.7% Catholic
13.8% Protestant

5.3% Other
7.2% None

Computer Literate

86.3% Yes

Email Use

86.9% Everyday

Internet Use

6.5% Rarely
4.6% Once every two weeks
16.3% Once a week
35.3% Every few days
37.3% Every day

Evaluation of HealthAware Substance Abuse Features

	Extremely effective	Effective	Somewhat effective	Not effective	Unknown
Quotes	11.1%	53.1%	34.6%	----	1.2%
Physiology	12.3%	48.1%	33.3%	----	6.3%
Interviews	7.4%	58%	29.6%	----	5%
FAQs	12.3%	43.2%	38.3%	----	6.2%
Referral		40.7%	48.1%	8.6%	

Evaluation of Tools

Find-A-Doctor:

11.8% would look for a doctor on the WWW
54.1% would not look for a doctor on the WWW
34.1% might look for a doctor on the WWW

Making an appointment on the WWW:

10.6% would make an appt on the WWW
71.8% would not make an appt on the WWW
17.6% might make an appt on the WWW

Educational effects of the website

Significant shifts in the numbers of correct answers were found on the post-test. For example,
On the post test students knew the area of the brain responsible for learning and memory ($p=0.02$) and the area responsible for thinking and decision making ($p=0.0001$).

Changes in Behavior and Attitudes

Participants in this study indicated some selective change away from risky behavior or attitudes. Missing classes because of drinking diminished from 38.5% to 28%. Unsafe sex after drinking diminished for both sexes from 19.2% to 8% for men and 10.9% to 6.2% for women.

5.1.2 Breast Disease

Age

30-39 37.5%
40-49 33%
50-59 24%
60-69 5%

Marital Status

Married 61%

Education

High school 21%
Bachelor's 22%
Graduate degree 44%

Income

Median 50-60K

Occupation

Administration 32.5%
Clerical 22%
Faculty 17.5%
Custodians 19%
Dining service 5%

Race

White 74%
Hispanic 10%
African-American 6%
Other 10%

Attitudes about Health Behavior

45% report that health is a priority
77.5% report having an annual clinical breast exam
54% report seeing their doctor once per year
89% report that they do not smoke

Breast self-exam

19% monthly
31% every few months
26% seldom
24% forget

Information Resources for Health Issues

61% report that the media is their primary source of information
21% report that their doctor is their primary source of information
75% are computer literate
85% have computer access at work
62.5% have computer access at home

Evaluation of HealthAware Breast Disease Content

	Agree	Disagree	Unknown
Easy access	47.4%	14.9%	37.7%
Content readability	61.4%	12.3%	26.3%

Effects of HealthAware on Health Behavior

52.7% were motivated to learn about breast diseases
53.8% reported that they became more competent in dealing with their health care professionals
8.8% reported that the recommendations motivated them to see a physician

Breast Self-Exam (BSE)

44.9% reported that HealthAware motivated them to do BSE
32.7% reported that BSE was already part of their routine

BSE technique

27% reported that HealthAware prompted them to change their BSE technique
23.9% reported that they already use this technique
49.6% reported no change in technique

Mammogram

50% reported that this is already part of their health routine
12.5% were motivated to have a mammogram 37.5% report that this was not a motivating factor

HealthAware recommendations

8.8% of women reported making an appointment as a result of the HealthAware
70.8% report that this is already part of their health routine

Information sharing (participants selected multiple categories)

34.2% shared HealthAware info with friends
36.2% shared info with families
30.3% shared info with co-workers
9.2% shared information with health care professionals
36.2% didn't share info with anyone

Focus Groups

2 focus groups were held, with 5-9 participants.
All female, BC employees and age 28-60.

General comments:

- very positive feedback and support for this website
- user-friendly, easy to access, easy navigation
- comment "I think somebody could navigate around without having a lot of computer experience"
- tools were interesting and especially useful
- they liked the fact that topics could be accessed from the top rather than scrolling through pages of info
- they did not like using a password
- raised questions about the validity of health information in chat rooms and message boards
- the content and recommendations were trusted because it came from a reputable source - Brigham and Women's Hospital
- participants felt empowered by the information
- felt it was a good reference and resource
- comment "With the way medicine is today, you've got to take it all into your own hands"
- participants in this group didn't follow-up with the doctors directly, but said that this website will help them to formulate questions for their next visit
- this was particularly helpful with the patient-physician interaction since the visit is so brief. They felt this was a good way to communicate, "need a website like this with reliable info to supplement the brief interaction".

Changes in Behavior and Attitudes

In the post-test, 25.4% (15) of the 59 women who were not performing breast self-examination monthly or every few months, reported that they began doing so. Another 8 women improved from "every few months" to "monthly" self-examinations. Of the whole sample, 21.1% (20) reported that they had improved their technique for BSE because of the HealthAware website. 46% (6/13 of the women >40, who had not had mammograms, reported doing so in the post-test.

5.1.1 Sports Injuries

Gender

72.2% Female
27.8% Male

Race

79.2% White

20.8% Other

Athlete type

14.8% Varsity
85.2% Non-varsity
All played varsity sports in high school

Computer Literacy

88.9% Yes

Email Use

99.1% Everyday

Internet Use

15.1% Several times/day
41.5% Every day
28.3% Every few days
13.2% Once /week

85% report that they were athletes in high school
74% feel that seminars on sports injury prevention are needed
75% of respondents had a injury that required a doctor's visit
33% had an injury that required a visit to the ER
15.6% of this sample was at risk for eating disorders (major motivation for participating in activities is to lose weight and eating habits fluctuate based on participation) - this sub-group is 100% female and non-varsity athletes.

Evaluation of HealthAware Sports Injuries Content

	Strongly Agree	Agree	Unknown
Easy access	33%	52.9%	14.1%
Content readability	-----	74.5%	25.5%

The students were somewhat enthusiastic about the educational value of the web site. The Sports Injury Prevention page motivated 51% to learn 56.9% reported that they felt more comfortable dealing with a sports injury; 60.8% reported that they learned new strategies to prevent sports injuries.

Among the respondents, 22.2% reported they would make a doctor's appointment using the web, while 79.6% would not. The availability of sports physicians here on campus perhaps influenced this response.

Changes in Behavior and Attitudes

Student participants in this study showed no significant improvement in preventive behaviors or attitudes. The great majority still felt that injury was normal to sports. 66% stated that they were motivated by the web site to prevent sports injuries. Employee participants expressed more interest in preventive behavior and made some important short-term changes.

5.1.4 Prenatal Care and Pregnancy

Age

Mean 26.9

Education

20.2% High school
43.7% Bachelor's degree
32.8% Graduate degree

Income

Mean 40-50K

Religion

54.7% Catholic
21.4% Protestant
3.4% Jewish
8.5% Other

Race

86.3% Caucasian
2.6% African American
4.3% Asian
4.3% Hispanic
2.5% Other

Marital Status

60.5 % Single
38.7% Married

Pregnancy

80.5% have not had a term pregnancy
19.5% have been pregnant

Smoking

11.9% currently smoke cigarettes
88.1% do not smoke.

Exercise

25% exercise three times a week
25% once or twice a week

Annual Checkup

47.9% see a physician once a year
37.8% see a physician more than once a year
10.9% see a physician every two years

Sources of Health care information

25.2% books
21% family members
17.6% physician
11.8% media
10.1% word of mouth

Computer Literacy and Access

94.1% computer literate
95.7% have access to a computer at work

Effects of HealthAware on Health Behavior

70.1% were motivated to learn about prenatal care
19.8% reported that they were motivated by the information to change their lifestyles
29.3% would search for a health care provider on the Web
32.7% would want to make an appointment online

Evaluation of HealthAware Prenatal care and Pregnancy Content

	Strongly Agree	Agree	Unknown
Easy access	38.4%	52.5%	9.1%
Content readability	35%	60%	5%

Focus groups
3 Focus groups were conducted with groups of 5-9 participants.
Participants were all female, BC employees, graduate students or fellows.

The women in all focus groups were unanimous in describing the outstanding features of the web site – comprehensive, contemporary information that is available 24 hours a day. They were also unanimous in noting that they would turn to such a web site in the future and would recommend it to friends and family as a valuable resource. Most noted that the site assisted them or would assist them in taking a more active part in their own care. For example, they found that they could get: "Quick answers to quick questions," "concrete answers to questions," and "timely answers." Consequently, access to the web site resulted and will result in fewer unnecessary calls to the prenatal health care provider. In addition the site helped the participants to become more of a partner in their own health care. For example, one currently pregnant woman commented: "Due to my education via the web site I now have more active participation when talking to my doctor."

While general assessment of the web site was overwhelmingly positive, when asked, the women made some suggestions for future improvement in production: provide more pictures and diagrams, more interactive functions, create a back home button to keep the user from getting lost in all the links, and give more information on the pros and cons of new technology like genetic testing. Many of the women expressed an interest in learning more about midwives and would have liked more information about the prenatal care providers.

Changes in Behavior and Attitudes
32% of the participants in this group reported exercising more, trying to lose weight. The few women in the group that smoked, said that they would now stop if they became pregnant.

5.1.5 Cardiovascular Disease

Computer Literacy
93.8% computer literate
6.2% not computer literate

Sources of Health care information
54.3% media
15.5% physicians
10.1% family

Annual Checkup
47.7% see a physician once a year
33.3% see a physician more than once a year
19% see a physician every two years

Smoking
92.4% do not smoke.

Exercise
64.4% exercise twice a week or more

Alcohol
37.1% less than once a month
32.6% one to two times a week

12.9% drink three to four times a week
9.8% drink five or more times a week
7.6% indicate they never drink

Effects of HealthAware on Health Behavior

55% were motivated to learn about cardiovascular health
52% of participants stated that the Cardiovascular Health web site motivated them to take preventive measures against cardiovascular disease. When asked to explain what types of preventive measures they had taken, most respondents said that they increased the amount of exercise they do and improved nutrition by eating less saturated fat. Some noted becoming involved in stress reduction techniques like yoga and "not taking work home."

Evaluation of HealthAware Cardiovascular Content

	Strongly Agree	Agree	Unknown
Easy access	12%	43%	45%
Content readability	20.2%	51.5%	28.3%

Focus Groups

Three focus groups were conducted with 5-11 participants in each group.
Participants included men and women employees who were primarily between 35 and 60 years of age.

General Comments:

- Participants liked having mediated medical information on the Internet. They found the web site easy to access and convenient, far superior to less well mediated sites on the Internet. As one participant stated, "Instead of having to go to the American Heart Association for one thing and to this for another thing, I liked having a lot of issues that pertained to my own health in one spot."
- Participants wanted the web site to include more information on prevention - nutrition and diet, suggestions for exercise plans, information on the relation between stress, cardiovascular disease, and health, and information about the relationship between emotions, cardiovascular disease, and health.
- The majority of the group said they were likely to turn to the HealthAware site in the future because of their present familiarity with it.
- Participants expressed concern that HealthCheck generated recommendations even when information like cholesterol or blood pressure was missing. They also requested more interactive evaluations such as high cholesterol, body fat, and diet.
- With regard to behavior and change, the majority of focus group participants stated that, given the fact they had healthy lifestyles, the web site reinforced rather than changed their behavior. One participant noted that she is exercising more after seeing the web site. Some participants said that the site got them to think about lifestyle choices and that that is an important first step in regards to change. In addition, none of the participants decided to consult a doctor after viewing the information on the web site. Finally all participants noted that the information of the site made them feel more informed and that this would enrich future conversations with doctors.

Results of the pre-test and post-test surveys demonstrate that viewing the HealthAware site generally enriched participants' knowledge about cardiovascular disease and the associated risk factors.

Changes in Behavior and Attitudes:
Specific reported changes in behavior were small but affected high-risk participants with a body mass index (BMI) of 25 or greater. Overall commitment to change toward a healthier lifestyle seemed high. 48.9% of the participants described positive changes in diet, alcohol intake, exercise and lifestyle

BC Conclusions

Areas of Consensus

Five areas of consensus about the HealthAware Program emerge from the data thus far (pre-test and post-test surveys, focus groups, interviews and personal communications).

1. *Motivation*. Use of the site was highly motivational. Even when participants were already informed , the website information confirmed health lifestyle choices. For some in every application area, the program reportedly motivated behavior change or seeking medical advice.
2. *Empowerment*. Use of the site increased the individual's ability to ask questions and share information. Participants felt more able to ask pertinent questions of physicians and other providers

3. *Credible Information*. The site ranked high among competing sources of information because it is seen to mediate legitimated medical facts. That a major hospital stood behind the site was important.

4. *Efficient Information and Communication.* Participants saw the potential for the website saving them time in information searches and in offering diverse functions, such as making doctor's appointments or having online medical consultations. The site offers convenient access without barriers of time or location. Links were particularly valued, as were risk assessments and other opportunities to personalize the information.
5. *Confidentiality.* The site raised important issues of privacy and control of personal information. By its content, the Substance Abuse Awareness application appeared to direct participants away from interactive web functions, such as chat groups, bulletin boards, and referrals that would identify them with the information. Yet concern with confidentiality also characterized employees' responses to other conditions not identified with deviance. In the Prenatal Care application, for example, pregnant women and those considering pregnancy described reluctance to view the site at work, for fear they might be discriminated against in job assignments. Men and women alike viewed their medical concerns as private.

5.2 BWH Studies

5.2.1 Usage Log Analyses

When the site first went live, usage was quite high:

	Apr - June 1999	Jul - Sept 1999	Oct - Dec 1999	Jan - Mar 2000	Apr - June '00
Total requests	197, 115	37,772	12,335	12,765	5297
Total visits	1,567	1,064	1,080	742	786

There was a sharp decrease in August, 1999, when the login/registration screen was implemented. We also received some angry feedback messages requesting "free" access to the site, since it was "free" to begin with. Users were reluctant to register, even anonymously; some users expressed willingness to register and participate in the online evaluation if there were incentives such as money, movie tickets, t-shirts, mugs (token of appreciation for their effort and time). The registration allowed us to interview users online and have them complete automated evaluations of the site and the interactive tools.

The decline after September, 1999, reflected the phasing out of the testbed at BC, and the ongoing process of incorporating the system into the BWH site as a routine service. The BWH web site is undergoing a redesign and a strategy for systematic access and promotion is not yet in place

5.2.2 Interviews and Automated Evaluations

One-on one interviews were conducted with users at BWH. A workstation was set-up in the lobby of the Center for Women and Newborns, a high traffic area in the hospital. A total of 219 subjects participated in these interviews. 25 registered users responded to the automated questionnaires.

HealthCheck (Risk Assessment):

- HealthCheck provided useful care options or guidelines 82%
- Guidelines and recommendations were easy to understand 97%

MedMail (Ask-a-Doctor or Ask-a-Nurse function):

- Would like to e-mail their MD 84%
- E-mail would help with health care decisions 61%
- Appropriate way to "talk" to a physician 74%
- Could replace a phone call or a visit 77%
  - 30% phone call & visit (questions, follow-up, prescription renewals)
  - 70% phone call only

Both physcians and consumers/patients felt that this tool would be more effective is the consumer/patient knew who the doctor was and if the doctor knew them. The information they could get as an anonymous user from a "BWH" doctor (not otherwise identified), is not considered highly useful.

Frequently Asked Questions, FAQs:

- Found answers to their questions 93%
- Would follow-up with MD based on FAQ info 83%

Referral Facilitator:

(linked to doctors and to other resources: courses, seminars, service descriptions, virtual tours, directions, etc.)

- Using HA was easier than using the phone 97%
- Learned about new resources 89%
- Improved access to resources 97%
- Top 5 resources were: directions, educational seminars and classes, parking information and virtual tours.

5.2.3 Referral follow-up

Follow up from BC testbed site

We encountered a number of difficulties in tracking subsequent follow up of patient care for BC users based on HealthAware interaction. Consequently, we could not effectively carry out the projected studies of this.

- BC offers a 13-week remedial rehab program for any student that is brought to the clinic or infirmary in an intoxicated state, so students avoid these services at all costs. The University health service provides care to varsity athletes; non-varsity athletes prefer to use their own physicians. In most cases, students have health insurance through their parents' plan and use health services off-campus. BC does not offer health services on campus for the topics other than those cited above; this campus is also very conservative and religious, imposing certain restrictions on student and campus life.
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- Staff and faculty have their own insurance and do not use the University Health Service (UHS) except for minor first aid, flu shots, etc. This makes follow-up and tracking use of services impossible.
- Students use their parents' health insurance for the most part, so care is accessed in very different locations. This created a major disconnect between content and service access/utilization and we could therefore not evaluate our model in the way it was defined.
- Students requested information on sexually transmitted diseases (STDs) because they felt that the WWW would be a safe way to obtain this and learn about services, but this conflicted with the administration; consequently, when students at BC have problems in this area, they go to Boston University's Health Services or Planned Parenthood
- Students requested more information and services for substance abuse and related matters. The culture at BC is such that if a student reveals a substance abuse problem, his or her parents are contacted immediately and the student is sent to the Dean for Alcoholism and Substance Abuse for a 13-week remedial course. Students on this campus cannot access any confidential services, such as peer-to-peer counseling or rehab. Students started their own Narcotics Anonymous group and AA group in a church basement off-campus.

- The campus underwent a downsizing program (project Delta) during the study which impacted on recruitment. People were worried about losing their jobs and so did not want to spend time on "frivolous" activities like surfing the web. There were also some concerns voiced about revealing one's health status at a time when the University was trying to cut costs. Would people at higher risk for breast disease or heart disease be the first to go?

Follow up from BWH general access

All calls and referrals from HealthAware are made to the Teleservices Department at the BWH. Online referrals and appointment requests were made available to the general public via HealthAware and the BWH web site in early 1999. Teleservices follows up on each request with a telephone call.

WWW transactions for 1999

	1503 (4.79% of all phone calls)
WWW appointments booked	256
WWW appointment requests	2.93%

WWW transactions for 2000 (01/01 - 07/10)

	838 (5.54% of all phone calls)
WWW appointments booked	190
WWW appointment requests	3.9%

- According to Teleservices, " a lot" of these referrals came from HealthAware and the site helped stimulate interest in this feature on the BWH website.
- We were not able to track patients because they chose to remain anonymous. We would need to set up a clinical trial where we follow a cohort for a certain period of time, and collect feedback from them and the providers. Since users were anonymous, it was impossible to know who logged on from which clinic and who the MD was. The site was indexed in various search engines such as Yahoo and Hotbot; usage logs revealed that users came from all over the world -- including the UK, Canada, Venezuela, France, South Africa, Germany, Netherlands, Mexico, Turkey, Australia and Brazil.BWH services patients worldwide, so it was not possible to determine which users booked and attended appointments.
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5.2.4 General comments

- participants trusted the content because it came from BWH
- they felt the content was easy to understand and it responded to their needs
- navigation was simple, even for first time users
- strong desire for local content in a local context; people want to know what their doctors think about treatments, prevention etc and want to communicate online within their own provider network
- chat sessions and message board are of limited use because they are not moderated and can be a source of misinformation.

5.2.5 Legal issues

When this project was started, no BWH or Partners-wide policies existed. We have worked closely with the Partners Office of General Counsel and developed an Intellectual Property Agreement for content providers, disclaimers for the web site, and a privacy policy.

6. Discussion and conclusions

This project has helped us define the requirements and characteristics needed for successful health information web sites designed for health care consumers. We discuss here the various problems and limitations facing the project, and its accomplishments and successes.

6.1 Problems and Limitations

This study faced a number of limitations owing in large part to the artificial testbed setting and the consequent inability to develop a critical mass of usage.

(a) Content
Because of constraints in the contract, funding was not available for either procuring external content or significant local development of content. As a consequence, we were unable to create a site with a broad base of content that would attract a critical mass of users with a variety of health and health care questions or problems.

Instead, therefore, we chose to focus on particular diseases and problems considered to be of high interest and relevance to our testbed site at Boston College. In order to at least address a spectrum of users ranging from students to faculty to staff, and with a range of computer literacy and educational levels, the five content areas described above were chosen, those relating to sports injuries and substance abuse of primary relevance to students, that relating to prenatal care primarily for married graduate students, and young faculty and staff, and those relating to breast cancer and cardiovascular disease to older faculty and staff.

A consequence of the limited number of topics covered is that the site could not be promoted as a comprehensive health and health care resource, but rather only in the context of the specific diseases and problems that were covered. Thus, the site was not the first source that a typical user would think of to seek answers to health questions, especially with the emergence of large national web sites such as DrKoop.com, WebMD, Intellihealth, and others. Constant promotion was needed to remind users of the availability of this resource for particular problems, which was difficult to sustain, and interest of users in terms of repeat visits was also difficult to hold, given the limitations of focus.

Our approach of tying the site to local health care resources had particular appeal, so that once a patient was referred into a health care system, a relationship with a practice could be developed, and the site could function as a portal to that practice as well as to related health and health care information. This of course requires that the user's interest be captured initially, so it has been successful only to the extent that we have been able to set up a portal strategy. That activity is now ongoing, spearheaded by BWH Marketing, and we expect that it will be successful. A number of web health content providers are now marketing approaches influenced by or that have adopted the HealthAware approach: offering health content for branding or co-branding by a health care system, and offering tools for integrating risk assessment and referral into the health care provider network. Examples are HealthGate and HealthVision.

(b) Follow up numbers
Because of limited use stemming from small range of content, and the special problems encountered at our testbed site at BC identified in section 5.2.3, the number of patients seeking actual follow up with health care practitioners (an expected small subset of all users in any case), was quite small, and originally projected study numbers were not achievable.

We tried to expand beyond the BC testbed community by offering the service more broadly for BWH users, but limited opportunity to promote the site broadly prevented large numbers from this source. A brief uptick of usage occurred when the HealthAware site was identified in a February, 2000, BWH advertisement in Boston Magazine, but this fell off within a month.

(c) Patient identification
In order to follow up subsequent patient visits and interactions with a health care provider and to determine effect of HealthAware on the subsequent process, we need to be able to identify the patient and the fact that the entry into the system came from HealthAware. To develop a denominator, we tried requesting user identification and contact information with consent from all users, but this request as a requirement for proceeding dramatically reduced usage. Asking for it optionally resulted in almost no entries. Based on this, we abandoned the request for identification for all users, and only requested this when a specific referral request was made.

6.2 Successes

(a) Information and attitude effects
As documented by the BC pre-use/post-use studies and BC and BWH focus group and usability evaluations, we were able to determine that the content was useful and that users gained specific knowledge and constructively changed attitudes by

the criteria identified. We further validated the importance to users of locally supported and endorsed content, and the ability to link to local health care resources and providers.

(b) Design
Our usability and design assessments enabled us to determine significant features which users seek in a site, appropriate educational level for content, and desirable navigation and interface features. Based on focus group evaluations, we believe that the HealthAware design met our design criteria well.

(c) Continuity
This project has resulted in adoption of a web strategy and plan at the BWH to make the kinds of capabilities developed in HealthAware available on a continuing basis, augmented by a corpus of external content. The strategy of creating a portal for the health care system or for particular practices, where content as well as interactive communication resources, risk assessments, and referral are provided, which was the basis for the HealthAware approach, is now broadly accepted by the BWH, and plans are now under way, led by BWH Marketing, and with the support of a BWH Web committee, to implement this capability. HealthAware capabilities are expected to be incorporated in the system that will be put in place.

The BWH is also building a Center for Patient Education (the Bretholtz Center) where consumers and patients can access health information and resources. Computer stations will be set up to provide content, risk assessment and referrals within the BWH provider network. The progress and success of the HealthAware project influenced the rapid progression of this effort. This center will include workstations using the HealthAware model as a result of our work. The Health Promotion and Education Committee is overseeing the development of this center. We presented to this committee at various stages, shared our experiences and results with them, and now sit on the committee.

(d) Expansion of content areas
We have demonstrated that good quality content can be developed for a disease/problem domain for costs on the order of $5K-10K, and that it can be maintained and updated for a fraction of that cost on an annual basis. Based on that, several clinical departments and programs are working with us to use the HealthAware tools and platform to offer content on their programs. These currently include Obstetrics and Gynecology, Cardiology, Nutrition and Asthma.

(e) Validation of approach
While our testbed experiment was necessarily limited as discussed above, we believe that this approach has had considerable influence on the marketplace, and is being validated by current marketplace trends. The comprehensive Web content sites such as DrKoop.com, Intellihealth, and WebMD, have all found that pure content provision is not a suitable foundation for a business. They and other newer entrants, such as HealthGate, HealthVision, and HealthyConnect.com are now pursuing a business strategy in which content is tied with local health care services and providers, as demonstrated and advanced by the HealthAware project.

(f) Usefulness of tools
The approach that we have developed for content management and the set of interactive tools for risk assessment, referral, and other functions is continuing to be used in our extensions to other content areas, and may have more broad applicability, although they need to be expanded and updated.

7. Project Web Site, Presentations, and Publications

The project is viewable at www.healthaware.org.

The following external presentations and publications related to this project:

1. Guillemin J, Nordstrom A. College women and drinking behavior. (submitted for publication)
2. Guillemin J, Behbakht F. Women and breast cancer detection: A study in medical information access by ethnicity and social class. Presented at the Eastern Sociology Society Meeting in Philadelphia, March 21, 1998.
3. Guillemin J. The HealthAware project. Presentation and demo at the American Sociological Association Meeting in San Francisco, August 1998.
4. Marlow A, Nastika D. Undergraduates and sports injuries. Surveys on risk taking. Presented at the National Association for the Study of Sports Sociology in Las Vegas, Oct 1998.
5. Guillemin J. The HealthAware project. Presented at the Ural State University, Yekaterinburg, Russia. Sept 14, 1998.

6. Ohno-Machado L, Boxwala A, Guillemin J, Keefe K, Sharp G, Rowland T, Ehresman J, Dicesare T, Sato L, Greenes L. Linking health education and health care service information via the WWW: The HealthAware project. AMIA Fall Symposium, 1998.
7. Kogan S, Ohno-Machado L, Boxwala A, Guillemin J, Tam J, Keefe K, Dicesare T, Schaffer J, Greenes RA. HealthAware: An integrated health and health care information network. Presented at the 7th Annual Digital and Multimedia Fair at Harvard University, June 2, 1998.
8. Boxwala A, Kogan S, Greenes RA, Ohno-Machado L, Tam J. Problem-Focused Organization of Health Information Resources. Presented at the Interactive Consumer Health Conference in London, Ontario Sept 10-11, 1999.
9. Kogan S, Ohno-Machado L, Boxwala A, Guillemin J, Tam J, DiCesare T, Schaffer J, Greenes RA. HealthAware: A Consumer Health Information Destination Which Links to a Health Care Delivery Network. Theater-Style demo at the Fall AMIA Symposium, 1999.
10. Johnson-Levetan C, Guillemin J, Behbakht F. Prenatal care: a study of attitudes and options (submitted for publication).
11. Guillemin J. The HealthAware project. Presented at the American Sociological Association Meeting in San Francisco, Aug 19-23, 1999.
12. The Healthaware Project. Written up in the BWH Bulletin, July 9, 1999.
13. Guillemin J, Joyce K, Behbakht F, Bergese I, Galvin P. Age, class and gender in the use of on-line preventive health care programs (submitted for publication)
14. Greenes RA, Ohno-Machado L, Boxwala A, Kogan S. Improving patient care, quality and access: The HealthAware project. Presented at the Internet and Society Conference, Harvard University demo funded by Intel. May 2000.

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